

Robert and Kristen Malfara

The M.O.R.G.A.N. Project



Robert and Kristen's son, Morgan, is affected by Aicardi-Goutieres Syndrome.

The Malfaras are the parents of 3 boys. Their youngest son, Morgan, was diagnosed with Leukodystrophy at just 8 months old. At that time, he was presumed to have

Pelizaeus-Merzbacher Disease. Like most parents in the same situation, the Malfaras felt lost, inadequately prepared, and had no idea where to turn for help. Doctors in their town of Melbourne, Florida, were unfamiliar with this rare orphan disease. When genetic testing expanded a few years later, it was determined that Morgan did not have PMD and was diagnosed with an "unclassified Leukodystrophy".

In 2001, the Malfaras wanted to honor Morgan by using their experiences to help other parents by providing them with the support and tools they needed, that cannot be easily found elsewhere. The Malfaras say, "In effect, through The M.O.R.G.A.N. Project, it was our turn to 'pay-it-forward' with what we had learned and help empower other parents in the same situation..." Their acronym stands for Making Opportunities Reality Granting Assistance Nationwide, and they feel that every child they help is just one more way to honor their Morgan and the inspiration he truly is! The Malfaras credit other experienced parents with providing them with the resources they needed throughout their journey as Morgan's caregivers. Through networking and sharing with other parents, they hope to light the way for others.

The M.O.R.G.A.N. Project is a proud funding member organization of the World Leukodystrophy Alliance and for the past few years they have been able to collectively make an impact on both research and awareness. However, as parents they want to be able to make an impact for the families that are living and dealing with this disease on a daily basis. They hope to accomplish this by serving on the LCN Steering Committee. They believe that this is a wonderful opportunity

for them to do something as a family instead of as an organization. They hope their input will be able to bring information and services to these families much quicker than they were ever available to their own.

It was not until earlier this year that Morgan was finally correctly diagnosed with Aicardi-Goutieres Syndrome. There is still, sadly, not a cure for Leukodystrophies so the Malfaras would like to see centralized centers of excellence available to all families affected by these diseases. These centers will offer them a multi-disciplinary plan of care and coordinated services all in one place.

Robert and Kristen reside in Melbourne, Florida.